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ABSTRACT

The booklet examines issues associated with autism in adolescents and adults. Teenagers with autism exhibit behaviors not unlike their nondisabled peers, and standard definitions of the syndrome may not be relevant at that age. Brief articles explore the range of emotions families may encounter with a young adult or adult who has autism, typical issues (such as the child's sexuality and community reactions), demands on the family, guidelines for selecting day programs and group homes, programing factors, ways to promote independence in adults with autism, vocational opportunities, guardianship, and estate planning. Excerpts of parents' experiences are included, as are poems of a young adult with autism. (CL)

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CHILDREN GROW UP:
Autism in Adolescents & Adults

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INTRODUCTION

As coordinators of the Autism Outreach Project, we have found a pervasive lack of information regarding issues pertaining to autism in adolescents and adults despite an overwhelming need. This booklet was developed in response to this deficit, and we are confident that it addresses many of the issues raised over the last few years. We are optimistic that this booklet will fill a gap in the existing pool of informational materials. We thank the authors of the articles in this booklet and appreciate their sharing with all of us their knowledge and expertise. We dedicate this booklet to the thousands of children and adults with autism in hope that their tomorrows will be bright.

May, 1986

Kathleen Meyers
Outreach Coordinator at
The Bancroft School

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WORKERS WHO HAVE AUTISM

Ruth Page

During the past 15 years, those who represent people with autism have worked vigorously to bring information about the symptoms of autism to many audiences; people who diagnose, people who teach, people who hire. Successes appear in several areas. Autism has been included in the federal definition of developmental disabilities, a working definition of autism appears in the current edition of the *Diagnostic and Statistical Manual of Mental Disorders*, six states have adopted an educational definition of autism, and the Office of Special Education has moved autism from the category of Seriously Emotional Disturbed to a more accurate placement.

These definitions, valuable as they are, describe the behavior of someone 30 months of age and younger and give little information about someone past his/her mid-teens. A comparison of the major points of the commonly used definition with observations of teenagers with autism will suggest some important differences.

1. *Disturbance in the rate of appearance of physical, social, and language skills.* By the time a prospective worker is ready for training or placement in a job, it makes little difference about the rate of appearance of these skills. It matters little if he could read the Yellow Pages before he was toilet-trained or that he never played patty-cake. What is important is the uneven development of physical, social, and language skills. Some workers with autism can do complicated assembly tasks because their phenomenal memory makes this possible and cannot sweep up the trash afterward because their faulty neurological makeup makes this impossible. Almost always social skills lag behind the work skills.

2. *Abnormal response to sensations. Any one or a combination of sight, hearing, touch, pain, balance, smell, taste, and the way a child holds his body may be affected.* In the young child these responses are clues which tell about areas of impairment and suggest ways to teach. In the young adult, these responses cause a normal-looking person to act in some abnormal-looking way and suggest that one look for ways to bypass troublesome areas. The excitement of meeting a new person may cause him to flap his hands or leap gazelle-like in the air. He may work quietly for a time and then for no apparent reason, jump up and run around the room. He might rock and make strange humming noises while otherwise using public transportation correctly, and if his behavior causes excitement among his fellow-passengers, it is more

likely to become more agitated than to stop. These highly visible manifestations of invisible disorders exert strong influence on the placement of workers with autism.

3. The third symptom, *absence or delay of speech and language*, has been dealt with in some fashion by the teens and modes of communication have usually been established. There is little likelihood of establishing speech in a nonverbal person. If no method of communication has been taught before, there is every reason to assign the highest priority to teaching a nonverbal system, such as signing, and to teach it in the most practical way possible along with the work skills.

4. The final diagnostic characteristic looked for in the young child is *abnormal ways of relating to people, objects, and events*. Perhaps this category is the one in which the greatest difference can be seen between the young child and the prospective workers. No longer is it accurate to say that they look through people as though they weren't there. As teenagers, they are very aware of other people, often standing too close and staring intently. If they can talk, they have the greatest curiosity about others, asking questions and making observations of the most personal nature. Most have learned the proper use for objects and are rather rigid in using them only in the way they think is proper.

   The final aspect of this characteristic is an abnormal response to events. In the young child, we see a rigid adherence to routines. This may pose a problem in the teenage years but teachers and parents have probably devised ways of teaching the young person to cope with, or at least tolerate, the nonroutine. These methods should be used and expanded. The autistic worker may be upset by the prospect of a Monday holiday if usually he works on Monday, but the anxiety may be alleviated by simply posting the notice on a calendar days in advance. The anxious response may be there but there is probably a history of dealing with the response which can be taught to the vocational teacher or the employer.

Teenagers who have autism are, in many ways, like their peers who do not have autism. For illustration, read the list compiled by parents of autistic teenagers in South Carolina of normal things their children did.

A. Eats as if his stomach were a bottomless pit, raids the refrigerator at every chance, consumes quantities of junk food.

B. Needs to be reminded to bathe, wash hair, put on clean clothes, and comb hair and even when he does, he manages to look untidy.

C. Needs reminders to clean his room.

D. Has trouble managing money.

E. Parents never know what he is thinking or what is troubling him.

F. Spends much time each day lying in front of the TV. It takes a lot of encouragement and nagging to get him outdoors or involved in other activities.

G. Unsure of self.

H. Appears clumsy and awkward, drops things, bumps into furniture, walks in an ungainly manner.

In short, teenagers who have autism are more like other teenagers than they are like diagnostic criteria applied to them when they were two and a half. Much of that criteria should be forgotten as their strengths and weaknesses for the world of work are assessed.

What should be remembered about these prospective workers is that they have some special abilities and skills to bring to the world of work and that there are some people and some systems that are doing things worth knowing about. Most efforts towards students with autism are typical and traditional and the only unusual aspect is that they are directed toward people with autism which in itself is not typical and traditional.

Questions are often raised in vocational discussions about those legendary characters of autism who hurt themselves and destroy everything in reach and require one-to-one attention. Some of today's workers were once those legendary characters but a persistent educational program giving them a variety of useful responses has diminished the massive tantrums. Several important factors have changed the prospects for the seriously involved person with autism. The most important is behavior modification which uses the most effective of teaching techniques to teach people new ways to act. Next is the development of community services, which keeps people with autism around people with better social skills and away from concentrations of people who have the same social deficits. In some people, autism has been accompanied by, or caused by, observable medical problems which could be treated. Usually the extremes of behavior vanish under treatment though basic impairments remain.

The problems that remain should not be minimized. An upset worker may hit only once, but if he hits the wrong person, his freedom and the future of the programs or office in which he works may be in jeopardy. The worker who irritates customers or colleagues by socially inappropriate remarks will

surely lose his job. An immense amount of supervision is required to keep these workers working and there are times when the most carefully constructed plans for fading out supervision do not work. It is important to remember that although the worker may need ongoing supervision, the supervisor may now be able to supervise an additional worker. Massive behavioral deficits should not discourage attempts to teach work skills because skilled teaching approaches have worked near miracles in changing disruptive behavior into learning and working behavior.

For workers with autism, future directions should include innovative use of their strong points, usually a willingness to do repetitive work and a fantastic memory; and innovative detours around their weak points which are generally a lack of flexibility and a lack of social awareness. Sheltered workshops may play a decreasing role in the work future of people with autism as other approaches emerge, but those workshops may be well suited for the person whose very handicap is in social interaction. For those workers it may be more desirable for them to focus their energies on being productive in a sheltered workshop than to ask them to expend all their efforts toward merely getting by in an environment that is too harsh for them to cope with successfully.

Some challenging, interesting, and likeable workers who have the label of autism are ready for the opportunity to work. Looking at them in new ways, forgetting what should be forgotten, and knowing that meaningful work is vital to meaningful life, will expand horizons for people with autism and for those who serve and care about them.

NATIONAL SOCIETY FOR CHILDREN
AND ADULTS WITH AUTISM
Information and Referral Service
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Washington, DC 20005
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FIFTEEN EMOTIONS TO DESCRIBE A LIFETIME*

Julia Helvey

HAPPINESS . . . at the birth of this child, and watching the tiny infant quadruple his birth weight in one year.

ANXIOUS . . . about the development that seemed delayed as Harold matured those first years.

RELIEVED . . . when he finally did something physically or emotionally that we had not seen. Crying, as an emotion, was not seen until age six.

SHOCKED . . . when at age 3½, Harold was diagnosed mentally retarded by "professionals trained to evaluate very young children."

THRILLED . . . to have him in a special pre-school program and seeing so much progress in only a few weeks.

SADDENED . . . when funds were dropped from his pre-school services and no replacement could be found.

ENCOURAGED . . . that a private pre-school would enroll our child. (This teacher was the first person to ever mention "autism." She also questioned whether or not he really was retarded.)

FEAR . . . as the first day of public school approached for our six-year-old. More fear on seeing an inexperienced teacher with 18 EMH children in one room, ranging from 6-8 years of age. No aide, no help, and more problems than one human could ever handle in such a situation. The teacher was replaced in a week.

DEFEATED . . . as teachers, administrators, doctors, and education officials continued to tell us what was best for our child. One placement in a classroom for severely mentally retarded children, we fought bitterly, but lost. In less than two weeks after the placement was made, teachers were telling us that wasn't the place our son should be educated. At least someone agreed with us – now to start over! Two different years; three different schools, complete with new teachers, specialists and classmates.

DELIGHTED . . . at the progress our son made when he was back in a situation with "normal" children. He has always copied any behavior he saw, and later, we were told even his walk was probably that of the children he was around. At age 4, he put puzzles together like a blind child he

observed. His ten word sentences went to two word commands when placed in a classroom with children who didn't talk, and a teacher who gave short commands repeatedly so she could be understood.

HORRIFIED . . . to learn after two years of progress, administrators were considering placement back with severely handicapped children.

UTTERLY DEFEATED . . . as we, as parents, were always told we were too close to be objective; even though both of us had degrees in elementary and secondary education, and we were the parents of an older, quite talented, child.

THRILLED . . . to have a teacher and an aide, at age 11, make progress in breaking into our child's mind; unlocking numerous mysteries. A teacher who seriously questioned the mentally retarded label that had followed our child through nine years of schooling.

APPREHENSION . . . about the future of our child. As parents, we are aware that our son's education is never going to be easy. But we are also aware we have come a very long way. At times it was a fight; we shall always hope it was for the good. Knowing other children needed services too, made it worth the effort.

ELATED . . . at the completely changed attitude of our child. Seeing a child that is maturing into a responsible young adult. Though always a happy child, he now feels good about his accomplishments. No more angry, upset feelings upon arriving home from school.

* Reprinted from the January/February, 1986 issue of the Advocate, the Newsletter of the National Society for Children and Adults with Autism.

YOUR CHILD WITH AUTISM GROWS UP

Dr. Carolyn Thorwarth Bruey

Families tend to evolve in an unusually standardized fashion: The beginning involves a single couple, who are eventually joined by one or more children. Of special note is the fact that the eventual phase of the family is to return full circle to the single couple again. The children have all grown to adulthood and left home, leaving the parents to pursue any goals which have been left to the wayside during the child-rearing years. And, of course, this time period also provides a much needed rest after years of supervising the youngsters as they passed through various "trying" times.

Not so for the families of the developmentally disabled. When their peers are off playing racquetball or traveling, the parents of developmentally disabled young adults are strapped with the responsibilities which their friends have long since discarded (e.g., babysitting). Nature's way is truly adaptive: When parents are young and energetic, they find themselves taking care of little toddlers or rambunctious teenagers. As they enter their "golden years", parenting becomes less taxing as the children reach adulthood and begin leading independent lives. Parents of developmentally disabled children, although they may in fact require that long-deserved rest even more, still must generate vast amounts of energy during the years when their energy reserves are close to depletion.

By this point, you are most likely ready to throw this brochure in the trash can (that is, if you have sufficient energy to do so!) But wait; the situation is not as bleak as it may sound. There are definite strategies which have proven useful for parents of developmentally disabled young adults. The experiences which you are struggling through are by no means unique, and fortunately neither are they insurmountable. The purpose of this brochure is to outline various issues which arise during the early adult years, and techniques which you can attempt in order to make these years less stressful for you and your family. The most typical issues are the following:

(1) "MY, SHE'S GROWN!"

Remember when your developmentally disabled youngster was just a little toddler, and she could even look adorable in the middle of a full-fledged tantrum? Now that she is full-grown, her size leads to various difficulties. If she is aggressive, it is no longer possible to hold her still; if she is non-compliant, it is harder to physically prompt her. At times it feels like her size has made it impossible to handle her. But there are strategies

which help. These include increasing the frequency by which you praise and reward your child for non-aggressive actions (e.g., appropriate asking for attention, hugs, etc.), using non-physical prompts (e.g., gestural and verbal prompting), and in cases where your child is truly placing others in physical danger, the use of medication.

(2) "OH NO–SEXUALITY!"

One of the developments which parents find extremely difficult is the upsurgence of their developmentally disabled child's sexuality. Public masturbation can occur frequently, and parents often worry about the inability of their children to express their sexuality in a "normal" manner. Most parents have found that teaching their young adult offspring to discriminate appropriate time and place for masturbation to be an invaluable tool. In terms of the developmentally disabled adult's ability to express their sexuality through sexual intercourse, unless the individual is exceptionally high functioning this is a dream which needs to be discarded. Parents need not worry, for their children can still achieve warm and loving relationships nonetheless.

(3) "COMMUNITY REACTION"

When your developmentally disabled six-year-old tantrumed in the grocery store, you may have gotten certain questionable glances, but when your twenty-one-year-old offspring begins to knock the goods off the shelves, the community reaction can be quite severe. Although most parents describe themselves as "hardened" to this type of scene, there is still a sense of dread at gut level. One method which has proven effective for some parents in combating this reaction is to redefine community reactions as a reflection of ignorance rather than hostility. In truth, most comments which on the surface seem overwhelmingly obnoxious are indicative of a basic lack of understanding. This was especially apparent when one parent was asked if her nonverbal adult autistic daughter was an "exchange student"! By redefining community reactions in this manner, parents are often able to react in a non-defensive manner.

(4) "FACING EVENTUAL POTENTIAL"

There comes a time when addition and subtraction become less important than teaching a developmentally disabled adult to dress independently, follow a simple grocery list, or cook a simple meal. This is usually a difficult acknowledgement for parents to make, for it implies an obvious ceiling to their child's growth. At the same time, many parents find letting go of the traditional academics as a time when they can observe their young adult offspring learning skills which will be functional rather than frivo-

lous. Gathering information regarding workshop settings or neighborhood storeowners who would be willing to take on a developmentally disabled adult to perform simple tasks can be a viable means of providing useful and productive activities for your child.

(5) "DIDN'T WE HAVE SOME OTHER CHILDREN AROUND HERE SOMEPLACE?"

Often, siblings of the developmentally disabled see leaving home as not only a time for independence from parents but also an unburdening of the responsibilities of having a brother or sister who demands so much time and attention. Consequently, those other children who you once termed "Our Little Helpers" are nowhere to be found. Developing independence is important for these nondisabled offspring; prohibiting this development would be detrimental. However, it is important for parents to lean on their other children when the stress level is rising. Requesting assistance from your other children is an adaptive response allowing you to have some time to yourselves.

(6) "FACING YOUR OWN MORTALITY"

Acknowledging our own mortality is never an easy task; it is especially problematic when gnawing questions concerning the future of your developmentally disabled offspring come into play. Fortunately, recent developments in financial planning have helped to alleviate some of these parental concerns. Group trust plans have begun in several states which combine many parents' monies in order to provide financial security for developmentally disabled adults. It is essential to contact a reliable accountant in order to obtain information on possible means of setting up your child's future.

(7) "RESIDENTIAL PLACEMENT"

For many families, placing their adult developmentally disabled offspring in a residential setting is a viable means of serving everyone's needs. Although this decision is inevitably characterized by feelings of ambivalence and guilt, in the long run parents feel content in knowing that their child is well taken care of and that they personally can have the time to attend to their own lives. As noted earlier, a return to the single couple is the general evolution of the family life cycle. If residential placement is considered, it is essential for parents to take the time to investigate various potential placements, and to assume that any effective setting will involve a long waiting list. When your child is living in a residential placement, do not assume that you have no right to visit. The general rule of thumb is to treat your developmentally disabled child's living arrangement as you

would your other adult offspring: Visit as often as you wish, and at the same time allow your offspring to experience a definite degree of independence.

Watching your developmentally disabled child grow into an adult can be a time of challenging issues and heightened concerns. Use the resources which are available regarding helping families of the developmentally disabled, and consider the guidelines outlined in this brochure. Rather than being a time of confusion and depleted enthusiasm, this phase of your family life cycle can actually be a time of lessened stress and increased personal contentment.

Dr. Carolyn Thorwarth Bruey specializes in children with developmental disabilities and their families, and provides assessments and evaluations, psychotherapy, parent training and consultation. Most services are reimbursable by insurance.

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THE YOUNG PERSON WITH AUTISM: DEMANDS ON THE FAMILY

Sandra L. Harris
Rutgers, The State University of New Jersey

Life in a family presents a series of challenges that we must meet if our family is to remain a source of strength and nurturance for its members. These ongoing challenges are normal developmental events that we all encounter. For example there are the difficulties as well as the pleasures of making a new born baby part of our lives; the tumult of raising an adolescent; the sense of loss that comes when children leave home; the tragedy of the death of a spouse. These are normal changes that most people face in their lifetime. The family of the child with autism must encounter both these normal events and the special demands that are created by the child's handicapping condition.

Every parent of an autistic child knows how difficult it is to learn the diagnosis, search for a good school, learn how to deal with the child's behavior problems, and so forth. Unfortunately, the special demands imposed on a family when a child is autistic do not end when the child grows up. In fact, some of the most stressful emotional experiences probably occur during the young person's adolescent and adult years. This stress is created in part by the need to locate appropriate services as the child outgrows the educational system, and by the failure of most communities to provide the full range of services important for the adult with developmental disabilities. Ironically, at an age when the young person should be increasingly independent, this lack of community resources may create greater dependence rather than increased freedom.

Changing Roles

Years of providing nurturance, love, support, advocacy, physical care, teaching and other seemingly endless efforts to meet the needs of the autistic person during the early years may leave some parents of older children feeling "burned out" or emotionally exhausted. Fortunately, most parents do not reach the point of total exhaustion by the time their child grows up, but many parents do feel increasingly burdened by their child's needs. This fatigue may reflect the need to change the kind of care one is providing. Parents of older children may find themselves better able to invest their efforts in advocacy, organizing community resources, or similar activities

than the continued provision of physical care or intensive teaching. It is legitimate for parents to make these kind of changes and understand that it does not mean that they love their child less, but that the child's needs and their ability to give have altered with time.

Episodes of Sorrow

The mourning process for a child's handicapping condition does not end when the child is young. There are episodes of grief and sorrow throughout the lives of the parents. Lynn Wikler found that for many parents, the developmentally disabled person's 21st birthday was second only to the time they learned the diagnosis as a source of stress. Whatever hopes parents may have had for the child when he or she was younger, by late adolescence or early adulthood, there is no longer any question about the extent of the handicap or the enduring effects of autism on their child's life. The future – for better or worse – is defined. In addition, the 21st birthday is an event that symbolizes adulthood and maturity in our society and therefore a painful reminder to parents of the limits confronted by their own young person. The 21st birthday may re-awaken a sense of sorrow and loss over all that the child will never be.

Leaving Home

Adolescence and young adulthood are times of increasing independence for most young people – the developmentally disabled child will rarely strive for independence and it therefore becomes the parent's responsibility to prepare the young person for a suitable degree of separation. This effort on the parent's part may be motivated by a number of factors including their recognition of the importance of the child's becoming as self-sufficient as possible, the realization that they, as parents, will not live forever, and the understandable wish of many parents to spend some of their life without the demands of full-time child care.

One implication of the separation process is that the family of the adolescent child must confront the question of an out-of-home placement and make a decision in the best interests of the child and the family as whole. There are no absolute rules about whether it is better for a young person to remain at home or live in a group home, foster care or other community setting. A plan should be made which respects the long-term needs of the young person and the family. Such decisions, no matter how wisely they are made, nor how clearly they are in the best interests of the child, almost always entail a certain degree of pain and doubt on the part of parents.

In addition to the decision about out-of-home placement, families confront other stressful events. Every parent faces his or her own aging as they

watch their children grow into adulthood. However, for the parents of an autistic child this stress is made even greater because they must grapple with the question of what will happen to their child after they, as parents, can no longer provide ongoing supervision. Many parents have posed to me in moving terms the question, "Who else will love him the way I do?" There is no replacement for a parent's love, although suitable out-of-home living arrangements, an intelligently written will, the continuing oversight of a sibling, relative or close family friend can ensure the ongoing welfare of the autistic adult after parents are dead or incapacitated. In order for parents to make these arrangements, they must however deal directly with that intensely difficult human issue of their own death. This emotionally laden confrontation with our own limits is one of the very stressful aspects of being the parents of an older developmentally disabled child.

Getting Beyond Change

Parents may find it helpful to recognize that the stress they encounter is not unique to them and that in most cases it is a normal, although painful transitional process which they can expect to surmount in a reasonable period of time. For most families, transitional crises do not last indefinitely – there is a period of stress accompanied by an active effort to resolve the problem and an ultimate resolution followed by a return to a more peaceful and stable family life. Sometimes talking to a religious advisor, family physician, close family friend or other important person can reduce the pain and speed the resolution of the conflict. Other parents of handicapped children who have dealt with the same problem are an especially good resource. For some families, where the problems are particularly intense or of a long standing nature, it may be helpful to consult a psychotherapist in order to reach a resolution from which the family may emerge as a stronger and healthier unit.

Sandra L. Harris, Ph.D., is a Professor of Clinical Psychology, Rutgers – The State University of New Jersey, and Director of the Douglass Developmental Disabilities Center, New Brunswick, New Jersey.

A SELECTION OF POEMS

By: David W. Eastham

David W. Eastham is a 21 year old man who has autism and lives in Ontario, Canada. The following poems are taken from his book of poems, "Understand". As he cannot write or speak, David produced his poems on Sharp's minicomputer Memowriter EL 7001. We thank Anne Grice, the editor of David's poems, Angela Cosentino (a special friend of David's), of the University Affiliated Facility, Rutgers Medical School, for sharing this with us, and most importantly, we thank David. In the words of Sally Borthwick, David's teacher, "We are very priviledged to have this opportunity to listen and hopefully . . . to understand."

UNDERSTAND

I want people to understand
I know it's hard to do
I think they can, if they try
Understand won't you?

Understanding is so hard
I long to see it real
I just hope, really hope
It's not a lost ideal

YOUTH SO SOBER

Youth need help
From every source
Help us find a way
See our needs
Hope you will stay
Help us find a way

Be there for us
Get to know us
See who we are

FOR DAD

I like happy people
Just like my Dad
He is my friend by the way
He is so smart and I love him so
He helps me every day

PLOW THE HAPPINESS

Lonely boy, do
Not fear
God will
Appreciate why
You're here

The sun does
Rise
The wind does
Blow

I love you boy
Under the sky

Perhaps you'll
Never talk or
Run
But you'll spread
Joy around for
Everyone

Use what God has
Given you
Plow the
Happiness
Too late for you

HOPE

You forget hope.
It is easy
But only hope will set you free.
You have to hope for the best.
Prepare for the worst
And perhaps pace yourself
To accept either one.

There is not much hope
For autism right now.
When they find a cure
I will perhaps be old.
Youth really paves the way
For old age
And the pavement will be set.

Just think
How terrible old age will be
On the parents
Of the children.
Do you think help
Will arrive in time?

TEACHERS

They are among
The angels
That a person
Knows

There
You see I've been
There
Touching early
Souls

Teach a person
Kindness
Your way is best
By far
Question your
Reasons
To help a kid
Become a star

MOTHER

Good mothers
Like you
Loving kind
Judge, you

Mum
Could I
Love hope too

Understand
Reason that
I love you
I love you

You try
Try
Yes, you
Really do

Please
Love stay
True

Your
Ever old
David

IN MY MIND

I try to pretend I'm
Normal as humanly possible
In my mind

I try to go to
Teaching
In my mind

Try my best
In my mind

Go for my license
In my mind

Get married
In my mind

Hope my dreams can
Come true

A LOOK BACK – A LOOK AHEAD

(Written by the father of a young man with autism, and an active advocate.)

As the father of a 25 year old young man with autism, I can testify that raising a child impaired by autism regardless of age, can be very difficult. Some say that it gets easier as the child grows up and, in part, that is true. But some of the difficulties seemed to increase as my son got older. As problems changed, so did public tolerance. Inappropriate behaviors which were passed over when my son was 6 or 7, became unacceptable as he grew into a young adult. The fact that my son looked much younger than he really was helped, but he had the strength of his youth, while we, his parents, were beginning to age. This was the point when our family came to realize fully, deep down, that autism is for life. The disability does not go away. And although special education and behavior modification had done much to ease the problems, they alone are not solutions. The energies of our family had begun to diminish. It was then, that we decided to consider residential placement.

In doing so, we discovered a two-faced problem: one face was practical, the other, moral: "Could we abdicate our God-given responsibility as parents?" In theory, our answers seemed clear: all that we could claim as our due, at best, is to provide the sort of environment in which our son could become all that he could, the sort of care he needed and deserved, where he could fully realize himself. And this is true whether or not he suffered from any handicap, mental or physical –

"the thousand natural shocks
That flesh is heir to", in Hamlet's words.

Our autistic son could not fully recognize himself in the nuclear family. Perhaps, if we had "aunts and cousins whom number by the dozens", all living with us, all loving and kind, it may have been possible to consider having our son continue to live at home with us.

The practical problem, on the other hand, was that there were (and are) no appropriate provisions for persons with autism in the State institutions. Our son would not have received the sort of services and care he needed to make the most of his life. If his behavior problems had escalated, he may have spent his life tranquilized – if that can be called living. This was not acceptable to us as parents who had spent most of our lives advocating for our son's education. We felt responsible for our son's well-being and wanted to safeguard a very heavy investment in care and education. We have the right to want the best for our son, regardless of his age.

Happily, we found an answer to this dilemma – a community based group home designed specifically to meet the needs of the adult with autism. When we first began, however, no such place existed. Nor did educational programs for students with autism, years ago for that matter. In fact, the absence of services for our son was not to stop us. We had been active advocates since our son was very young and with guidance from a group of committed service providers, we helped to establish a private school for the emotionally disturbed (then we still believed our children were "emotionally disturbed"). It seemed clear to us. Our efforts had paid off for our son in terms of an educational program that better met his needs. We focused our energies on establishing a group home in the community that would meet his needs.

There are several group homes now, but then there were none. In New Jersey, most are run by private agencies which are funded through the Department of Human Services. We encountered many obstacles in establishing a group home: long, hard negotiations with State agencies, the residents of neighborhoods, who (still) believe that those with a developmental disability are dangerous, the very strict (and necessary) building and safety codes, and the gross shortage of daytime work activity sites which are appropriate for persons with autism, just to name a few. It was hard work, but well worth it.

Once the home had been established, my son moved in. I know his progress is due in part to my continuous efforts, as well as all the help he is getting from the group home staff. He seems happy. Even so, every now and again, I feel as though I am guilty of some crime. As Pascal said, "The heart has its reasons that Reason does not understand."

Putting emotions aside and going on is never easy. By nature, advocating for the child you love is emotional business. My son's needs are being met, but my work cannot stop. I am still an active advocate and since parents are the most effective advocates, and are the ones who are willing to provide the necessary push and volunteer their time and labor, it is us, parents, who must continue to advocate. We must channel our emotional energy into active advocacy and start planning today for our children's tomorrow.

GUIDELINES TO ASSIST FAMILIES AND PROFESSIONALS WHEN LOOKING FOR DAY PROGRAMS AND GROUP HOMES FOR ADULTS WITH AUTISM

The following guidelines have been developed by the New Jersey Task Force on Autism and endorsed by the New Jersey Council of Organizations and Schools for Autistic Children and Adults, to assist families and professionals in identifying appropriate programs and services for persons with autism.

These guidelines reflect factors which have been demonstrated to contribute to quality services for individuals with autism. A program, however, need not meet each guideline in order to provide effective services.

Certain guidelines will be more or less important depending on the circumstances affecting the particular agency and each person with autism and his/her family.

GUIDELINES PERTAINING TO DAY PROGRAMS:

FACT: **Adults with autism have the right to attend appropriate and effective programs in the least restrictive environment and to benefit from participating in community activities.**

Does the program foster community-based awareness?

Are the participants involved in community shopping, banking, etc.?

Is there a system of money management?

Is the quality of work completed in the program important to the participants and staff?

Could manufactured items be sold competitively?

Are sub-contractors satisfied with the quality of the participant's work?

Is the program open all year? Are the hours close to a 30-35 hour work week?

What are the strategies and policies for normalization?

Are the programs age-appropriate?

Does the program appear to be sensitive to the level of development of the participants?

Are ancillary services such as speech therapy provided?

Does the program focus on the concept of employability?*

FACT: **Adults with autism require individualized planning to ensure appropriate treatment. Research has repeatedly demonstrated the efficacy of data-based treatments. Data allows for accountability and provides an objective means of evaluation.**

Is the program individualized to meet the unique needs of each adult?

Is there evidence of systematic implementation of the participant's Individualized Habilitation Plan (IHP)?

What is the staff-participant ratio? Is one-to-one available?

Is there objective (data-based) observation, measurement and evaluation of behaviors and of the effectiveness of programs?

FACT: **An effective staff ensures effective treatment.**

Are the staff experienced and appropriately trained professionals? For example, do they receive an ongoing formal training program in effective teaching and behavior management strategies?

Is there a good system of organization and supervision of staff?

Are they working appropriately with the participants?

Is it evident that there is adequate staff supervision and feedback?

FACT: **It is important for parents, guardians, and professionals to explore what exists and make placement decisions based on what is best for the person with autism.**

Is there a central philosophy of training and programming?

Can all staff members explain and support it?

Do you as a parent/guardian or professional support it?

FACT: **Suspension for inappropriate behavior is detrimental to the development of an individual with autism.**

What are the program's policies relative to crisis intervention and suspension?

FACT: **Accreditation ensures adherences to standardized basic and legal guidelines (e.g., building characteristics, fire drills, balanced lunches) and demonstrates a professional attitude regarding provision of services.**

Is the program approved by the Division of Developmental Disabilities, or is it a member of an organization whose guidelines you can refer to?

FACT: **It is important to have an effective governing body which enhances communication and ensures accountability.**

Is there a governing body? What is its role? Do you have access to it?

ADDITIONAL GUIDELINES PERTAINING TO GROUP HOMES:

The guidelines described previously for day programs will in most cases apply to group homes as well. The items below represent additional factors that should be considered when evaluating a potential group home placement.

FACT: **Individuals with autism who need residential services require specialized services which are distinct from those required by other populations.**

Is the program accessible to and does the program make use of existing community resources?

Does the group home look like other houses in the neighborhood?

Does the group home have a home-like atmosphere?

How does the group home promote normal daily living?

Does the group home offer adequate recreational activities in the home and provide opportunities for recreation in the community?

FACT: **Group home programs must be individualized to meet the unique needs of each person living in the home.**

Do all of the individuals with autism in the home participate in ongoing activities that appear to be appropriate to their skill level?

Is the group home program coordinated with each individual's day program?

Does there appear to be enough staff to provide adequate supervision? Is one-to-one available if needed?

FACT: **Individuals with autism will benefit from a group home program that provides the individual with frequent opportunities to learn new skills and encourages the individual to assume responsibility for his/her needs.**

Is there evidence of an active teaching program in the group home?

Do all of the individuals in the home participate in activities that contribute to the daily operation of the home?

How are behavior problems handled in the group home?

FACT: **Group home staff require specialized skills to ensure that the individuals with autism in the home receive appropriate, effective services.**

How are the group home staff hired? Does the program have criteria governing the selection of staff?

What pre-service and in-service training are provided to group home staff? Does the staff receive formal training in effective teaching and behavior management strategies?

How does the group home evaluate the performance of its staff?

FACT: **Group homes function more effectively when the parents'/guardians' rights and responsibilities are clearly understood by the parents/guardians and the group home staff.**

What expectations do the group home staff have regarding the role of the natural parents if their son/daughter is to be placed in the group home?

Is the program open 365 days per year? If the program closes, what provisions are made for families who need assistance at these times?

How are parents involved in treatment planning for their son/daughter with autism?

Is there a positive, open atmosphere in the group home?

Are group home staff receptive to questions, concerns, complaints, etc., raised by parents/guardians?

FACT: **Group homes are licensed to ensure that each home meets a set of standards, and the group home is regularly evaluated against this set of standards.**

Is the group home's license in evidence? Are the standards governing this license available?

Are the policies and procedures of the group home agency available?

What are the group home's procedures for intake and discharge of individuals with autism?

How are health and safety considerations handled in the group home?

Is the home neat, clean, safe, and in good repair?

Is the home large enough for the number of people who live in it?

Is the group home affiliated with a professional organization? Are there criteria governing membership in the organization? Does the organization have an accreditation/certification process?

FACT: **It is important to have an effective governing body which enhances communication and ensures accountability.**

Is there a governing body?

What is its role?

Do you have access to it?

*Added by the Autism Outreach Project.

FACTORS INVOLVED IN PROGRAMMING FOR ADOLESCENTS AND ADULTS WITH AUTISM

Karen Storm and David L. Holmes
The Eden Programs

In order to fully address the needs of adolescents and adults with autism, it is necessary to explore the similarities and differences between children and adults with autism, available options for the adult, and how to identify an appropriate, comprehensive training program.

Are adults with autism just bigger and older children with similar needs, or do their needs change? In many ways, adults and children with autism have similar needs. The adult, as does the child, requires a consistent and structured behavioral program with a continuing need for speech and language therapy and home training. Other similarities include the individualization of programs, e.g., "next steps" must still be based on prerequisites or already acquired skills, and compliance and cooperation must continue to be stressed. Further, consistency between the work and home environment, whether the home is with one's family, in a group, or an alternate living arrangement, must exist.

Differences between programs for the child and the adult can be clearly seen when dealing with the age appropriateness and functionality of the individual's programs. An adult's remedial curriculum must continue to include self-care and social skill development, however, academic skills should be deemphasized except as they pertain to survival in the adult world. "Survival academic skills" include sign reading, following simple written directions, time concepts, money exchange, signing one's name, etc.

The benchmark for determining the appropriateness of a program for an adult with autism as opposed to one for a child takes into account the age and survival needs of the individual. In short, will the training focus for the adult allow him/her to succeed at competitive employment, supported employment, sheltered workshops, or an adult services program? It is often very late to begin considering skill development for survival in the adult world when the person becomes an adult. Rather, the adolescent's programs must be geared towards these goals. In adolescence, an individual with the potential for competitive employment will have a greater need for continued work in functional academics such as money and time concepts than the individual whose abilities are more in keeping with a more sheltered work environment.

What options are available in terms of remedial programs, sheltered work placements, supported and competitive employment for the adult with autism? At Project W.E.R.C., Inc. we believe in options for adults with autism as well as "safety nets" for those who have gaps in their employment record due to layoffs, behavioral problems, etc. Project W.E.R.C. (Work, Education and Resource Center), for adults with autism, with central offices in Princeton, New Jersey, provides many options to adults. Specifically, there are three levels leading to competitive employment. At one level, individuals work on *manufacturing* skills, i.e., the production, from raw materials, of crafts, ceramics, and woodshop projects. Durational tasks, product completion and quality control are all taught and reinforced at this level. At level two, there is added the factor of rate of production, as the individual is involved in the completion of *sub-contract work* from local industries. An adult who is able to complete manufactured and sub-contract work satisfactorally, and is able to control impulsive behavior is placed in a *supported employment* setting. One to four adults are placed in a competitive work site with a full time supervisor. This supervisor instructs, as well as reinforces appropriate work skills and is able to deal with any inappropriate behaviors that may occur. An individual who no longer requires the immediate supervision is then prepared for independent, *competitive employment*. In order to control for any gaps in programming, a "safety net" exists at each level, whereby adults who have progressed to higher levels can fall back to earlier levels as the need arises.

An advocate seeking an appropriate program for the adult with autism should look for the following: the program should be individualized to meet the needs of each participant; the program should offer age appropriate activities and ancillary services such as speech and language therapy and home training; the staff must be experienced and well trained in effective teaching and behavior management strategies; IHP (Individualized Habilitation Plan) should be systematically implemented for each individual in the program; the program should be open year round (12 months), 30-35 hours per work week, and provide a low participant to staff ratio (maximum 3 or 4 to 1 with the option for 1 to 1); community based programs with an emphasis on supported or competitive employment should be given highest priority.

Remember, many factors contribute to a successful program; however, competent, caring leadership with an enthusiastic staff and supportive families and guardians make for an environment conducive to continuous progress by the adult with autism.

Adults with autism can be productive, contributing members of society when provided with challenging goals in conjunction with appropriate services to ensure the attainment of these goals.

Karen Storm, is the former Director of Adult Services at Project W.E.R.C. David L. Holmes, is the Executive Director of the Eden Programs, One Logan Drive, Princeton, NJ 08540, which include Project W.E.R.C.

A STRATEGY FOR DEVELOPING INDEPENDENCE FOR ADULTS WITH AUTISM

Michael J. Tyburczy, Joylyn G. Bailey, Lynn E. McClannahan
Princeton Child Development Institute

The degree of independence that a young adult with autism achieves is related to the skills he/she has developed. The need for effective, data-based programs from early childhood is essential in order to lay the foundation for independence in adulthood. The goal is to provide intervention that assists them in acquiring new skills and learning to control inappropriate behaviors.

At the Institute's Family Focus group homes, initial programming emphasizes the development of family-living skills through a structured schedule of daily activities. Skill-building activities include instruction in how to prepare meals and snacks, wash and fold laundry, select clothing, enjoy leisure activities, and greet guests, as well as how to perform a wide range of other family living skills. As an individual develops skills, and learns to sample and enjoy various activities, he/she is also taught to make informed decisions about his/her life activities. If an individual can state a preference between TV shows or favorite snacks and meals, he/she can begin to make the choices which allow for a greater degree of independence.

Most people have a system that helps them manage the activities of daily life. Checklists, appointment books and calendars are used as prompts to initiate and complete necessary and preferred activities. These organizational techniques can be modified in order to help developmentally disabled persons manage their own lives. When an autistic person has developed a repertoire of life skills, he/she is ready to learn to use a "schedule of independent activities." Such schedules can help developmentally disabled people manage their self-care, leisure time, employment and other activities of daily life. In order to ensure success in following an independent schedule, the initial activities chosen are ones that the person: a) has mastered, b) can complete without direct and immediate supervision, and c) frequently selects. Activities are ordered from least to most preferred, and participation in the last activity is contingent upon successful completion of all of the preceding activities.

An initial schedule of independent activities might include the following: Vacuuming a room; coloring, painting, or using pastels; listening to

music; and having a snack. These activities are listed together with the time each activity should begin. If a client cannot tell time, he/she can learn to set a kitchen timer, and the tone serves as the prompt to move to the next activity; alternatively, completion of an activity may function as a prompt to move on to the next activity. Individuals who cannot read may learn to follow a picture schedule; i.e., pictures of the materials or activities are placed in a notebook, one to a page, and as each activity is completed, the learner turns the page and initiates the next pictured activity.

When teaching a client to use an independent schedule, as with any new skills, he/she should be provided with a high rate of reinforcement for each component of the chain of activities. For example, the client may be reinforced for beginning the schedule on time, checking his/her watch, completing the activity, putting materials away and moving to the next activity. Reinforcement is carefully faded until ultimately, the client receives a reward only after successful completion of the entire schedule. In teaching schedule following, gestures and manual prompts are used more frequently than verbal prompts, and these are faded as rapidly as possible so that the client's own behavior prompts the next response in the schedule following response chain. Next, the therapist begins to fade him/herself as a prompt. This step is important since the goal is to have the person learn to follow the schedule independent of prompts from others; gradual fading promotes the generalization of the schedule-following skills the client has learned. Thus the therapist leaves the room for increasingly longer periods of time, providing the client with opportunities to be on-task without supervision. When the client is proficient at working independently, the number of scheduled activities may be expanded. Intermittent spot checks and intermittent rewards help the client to maintain independent engagement in scheduled activities.

The ability to state preferences and make decisions about life activities increases the measure of dignity young adults with autism can enjoy. The next step in programming emphasizes teaching the individual to select the activities he/she would like as part of the daily schedule. The client is given a "blank" schedule (i.e., one with only times and blanks for activities), and a list of work and leisure activities from which to choose; he/she chooses the activities and places them next to the times. The therapist helps the client make appropriate choices, and shapes on the decisions he/she makes, providing rationales for various decisions, if the client's receptive language skills enable him/her to understand them.

Some young adults in the Family Focus programs have learned to follow schedules of independent activities for as many as six hours. For them,

the alarm clock is the first prompt for following a schedule of independent self-care activities. The data indicate that they can make appropriate choices of activities, and can remain independently engaged in these activities. When these individuals broaden their repertoires of skills, learn to use schedules as prompts for moving from one activity to another throughout their waking hours, and continue to make appropriate decisions regarding their schedules, their options for leading lives of greater independence will be greatly enhanced.

Michael J. Tyburczy is the Adult Program Coordinator, Joylyn G. Bailey, the Consultation Coordinator, and Lynn E. McClannahan, the Director of the Princeton Child Development Institute, 300 Cold Soil Road, Princeton, NJ.

VOCATIONAL OPPORTUNITIES FOR ADULTS WITH AUTISM

Kathleen Meyers
The Bancroft School

Upon completion of their education, young men and women with autism will embark upon a new dimension in their lives: the transition from school to working life. A necessary first step to the transition from school to work is an adequate information base which describes the nature and scope of postschool services at both the state and national level.

In New Jersey, the predominant model of service delivery for adults with autism is the Adult Training Program, which is funded through the Division of Developmental Disabilities (DDD), NJ Department of Human Services. Normalization into adult life is the key to the Program, with the goal of maximizing the potential of individuals served so that they may become more independent. Adult Training Programs concentrate on delivering services in three basic areas: 1) Work Activities (i.e., vocational services); 2) Practical Arts (i.e., independent living activities); 3) Personal Awareness (i.e., daily living skills, leisure activities). This type of program is provided to individuals with developmental disabilities who are ineligible for services provided through the Division of Vocational Rehabilitation Services (DVR), NJ Department of Labor, because of their level of functioning and adaptive behavior.

While most Adult Training Programs serve individuals with all types of developmental disabilities, there are a few Adult Training Programs designed specifically to meet the needs of adults with autism. In addition to providing the core services mentioned above, most specialized programs for the adult with autism focus on the concept of employability. After systematic analysis of potential jobs and job sites, highly structured, individualized programming geared toward establishing skills necessary to gain access to work-oriented programs is delivered. Program goals focus upon providing job placement, job site training, and ongoing support services.

In certain locations, DDD also offers the Crew Labor and Production Project (CLAPP). CLAPP emphasizes the development of vocational skills and prepares workers to move into an actual work setting.

In addition to services provided through DDD, DVR offers Sheltered Workshop Programs and Work Activities Training Center (WATC) Programs. Sheltered Workshop Programs provide job training and long-term

noncompetitive employment in the fields of labor and industry. This program was designed for workers capable of producing work of economic value, but not at the pace required in the competitive labor market. WATC Programs on the other hand, were designed for workers not yet prepared to enter a sheltered workshop program. In addition to vocational skills, WATC Programs also provide training in social and daily living skills. Wages earned in Adult Training Programs, Sheltered Workshop Programs, or Work Activities Training Center Programs are contingent upon subcontract work and/or the sale of items manufactured in the program.

Nationally, the newest concept in adult service provision is supported employment. Basically, the idea of supported employment is to provide an individual with the level of support needed to successfully participate in a community work setting. Supported employment is *paid* employment for individuals who previously were believed to be unemployable, and who require ongoing support to perform in a regular work setting. The four basic models of supported employment are the supported jobs model, the benchwork model, the mobile crew model, and the enclave model.

The most common supported employment model is the *supported jobs model*, which initially provides training and support on a one-to-one, staff-to-worker ratio in a community job. Depending upon the needs of the individual, this intensive level of support may be gradually faded as the individual becomes more proficient in the employment situation. This model builds in long-term support as professional staff locate jobs, match and train individuals to perform those jobs, and provide ongoing and regular support. Workers receive commensurate wages for work performed.

The *benchwork model* provides employment in benchwork assembly and is performed in a program's own work space. While the model relies on contract work, it is designed to specialize in a single commercial area rather than diverse subcontract jobs, and provides approximately a one-to-five, staff-to-worker ratio. In addition to training on contract tasks, the benchwork model also provides training in community and social skills. Earned wages range from approximately $45 to $90 per month.

The *mobile crew model* provides employment in building and ground maintenance, and is operated from a program van. Approximately five individuals with handicaps and one nonhandicapped supervisor are employed in each crew, and perform jobs in community settings. A general manager provides service to the crew, as well as management functions. Earned wages average $80 to $185 per month.

The *enclave model* provides employment in regular industry settings

for up to eight workers with handicaps who are trained and supervised by a nonhandicapped, specially-trained supervisor. Workers receive commensurate wages for work performed.

The concept, and more importantly, the success of supported employment is exciting. In fact, the placement of workers who have a developmental disability into employment situations is a major federal priority. Unfortunately, those with autism have received the least consideration for vocational preparation and participation, despite evidence that these individuals can learn the skills necessary for success in nonsheltered work environments. Fortunately, there is ground for optimism – the national trend toward employability is beginning to penetrate New Jersey specialized services for adults with autism and there are model programs in a few other states as well.

Supported employment is a desirable option to traditional service models, particularly when one takes into consideration the problem of generalization experienced by many who have autism, research on the employment capability of those with severe handicaps, the need for integration into the labor force, and an ever growing problem of increased demand for service. Ultimately, the availability of employment rests on the willingness of employers to hire workers with autism. However, parents, service providers, and other professionals must initially lay the foundation by disseminating the knowledge and technology regarding vocational preparation and placement of people with autism. The combination of effective advocacy, improved skills, and innovative services will allow men and women with autism to participate productively in the labor force.

To apply for adult services in New Jersey, contact the Regional Office of the Division of Developmental Disabilities, NJ Department of Human Services or the District Office of the Division of Vocational Rehabilitation Services, NJ Department of Labor, at the beginning of an individual's last year in the education system.

For additional information, contact the Autism Outreach Office nearest you.

Kathleen Meyers is Coordinator of The Autism Outreach Project at The Bancroft School, Haddonfield, New Jersey.

THE RIGHTS OF PERSONS WITH DISABILITIES CONCERNING GUARDIANSHIP*

What is a guardian?

A guardian is a person who has legal authority to make decisions for another person.

As a parent, am I automatically the guardian of my child?

Yes, the law presumes that all children under the age of 18 are incompetent and gives parents the authority to make decisions for them. This is true whether or not the child is mentally disabled.

Am I automatically the guardian of my child with a mental disability after he or she reaches age 18?

No, the law presumes that all persons 18 or over are competent to make their own decisions. The right to make decisions for one's self is very important. Only a court can take that right away.

Do all adults with mental disabilities need guardians?

No. Many are able to make decisions for themselves.

How can I become the guardian of my adult child with a mental disability?

Anyone seeking to become guardian must bring a court action supported by the reports of two experts. This usually requires the assistance of an attorney.

What does the court consider when determining the need for a guardian?

The court looks to the nature and severity of the disability and whether the person can make decisions for him/herself. The court also makes sure that the person who seeks to serve as guardian will act in the best interest of the incompetent person.

Who is usually appointed guardian?

The law requires that the court give first priority to parents and spouses, then to other relatives and persons interested in the welfare of the incompetent person. Normally, the only time a parent or spouse will not be appointed is when there is a history of abuse or neglect.

Are there situations when a parent might ask someone else to become guardian?

Yes. Parents might ask a relative or close friend to be guardian if they believe that person can fill the role more effectively. This might be the case when the parent is elderly, incapacitated, or lives a great distance from the ward.

Can I appoint a guardian in my will to make decisions for my child after I die?

Yes, if you are already the guardian of your child. If your child is under 18, the appointment will last until age 18. If your child is over 18 and you have obtained guardianship through the courts, the appointment you make in your will will last indefinitely. Be sure that the person you name is willing to serve.

As guardian, can I delegate my authority to make decisions for my child to someone else in my absence?

Yes. The law permits guardians to delegate that authority for up to six months. This is done through a document known as a power of attorney, a written statement signed by the guardian in the presence of a notary or attorney. It is like a letter and should state the name of the ward, the guardian, the person to whom authority is delegated, the period of time the document will be effective and any other conditions imposed. This can be useful in situations where you cannot be reached quickly or easily to make decisions on behalf of your child.

What is the difference between a guardian of the person and a guardian of the property?

By law, guardians can make two different kinds of decisions. The first are personal and include decisions about where to live or whether to have surgery or other medical procedures. Making this kind of decision is the function of the guardian of the person. The second concerns financial decisions such as whether to sell a home or how to invest money. Making this kind of decision is the function of the guardian of the property.

Usually both functions are given to the same person, but sometimes they are not. When seeking guardianship for your child, make sure you obtain both.

Are there any limits on the types of decisions a guardian can make?

Yes. A guardian cannot consent to sterilization of the ward without court approval. Also, life-sustaining treatment cannot be withheld, except in very extreme situations, and then only with proper authorization.

Is there a way for a parent to obtain guardianship free?

Yes, if your child receives services from the Division of Developmental Disabilities (DDD, formerly the Division of Mental Retardation). A recent change in the law requires that DDD evaluate each person it serves to determine whether he or she is competent to make decisions. If DDD believes that a client is incompetent, it must request the court to appoint a guardian. It must also notify the family and invite them to appear in court where the Public Advocate will represent the interests of the allegedly incompetent person. The parents or other family members may be appointed guardian if the court agrees that one is needed. DDD will be appointed guardian if no family member or friend is available.

If in the past I allowed DDD to assume guardianship of my child, have I lost the opportunity to become my child's guardian at a later time?

No. By 1990, DDD will evaluate all of the 6,800 cases in which it is serving as guardian, and following the procedure outlined in the preceding question, parents will be notified when this begins.

Are there instances where a person who needs a guardian may not have one?

Yes, if an adult's parents do not seek guardianship and that person is not receiving other services from DDD, he or she will be without a guardian.

Are there dangers in not having a guardian when one is needed?

Yes, and they can be very serious. For example, in the case of a medical emergency, a doctor or hospital may refuse services to a person who is incompetent unless a guardian provides consent.

Are there other legal matters that should be addressed at the time parents obtain guardianship for their child?

Yes. They should make a will and plan how their money, property, and other assets will be distributed when they die. This is important because money or other assets left to a person with a developmental disability can effect eligibility to receive necessary services.

The Public Advocate recommends that parents get professional help in such estate planning. The Public Advocate does not provide this service. It will, however, make a list of publications on estate planning available on request.

Where can I get more information about guardianship?

Write or call:

Division of Advocacy for the Developmentally Disabled
NJ Department of the Public Advocate
CN-850
Trenton, NJ 08625
(609) 292-9742

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QUESTIONS AND ANSWERS ON ESTATE PLANNING*

Herbert Hinkle

What is estate planning?

Simply, it is a process by which a parent seeks to guarantee that the maximum resources possible will be available to his handicapped son or daughter.

How large must an estate be before estate planning is necessary?

There are no limits; even when the estate is modest, planning is essential to ensure that assets are used wisely.

Paradoxically, because many essential governmental benefits are available only to financially needy mentally impaired people, a disabled person who inherits money might be worse off than someone who inherits nothing.

Supplemental Security Income (SSI) and Medicaid, for instance, are available only to people with virtually no assets. But a modest inheritance – say $10,000 – can make a person ineligible for such programs and yet be insufficient to compensate for the loss of those benefits.

There are legitimate ways to ensure that the handicapped person receives maximum benefit from the estate, without depriving him of important governmental benefits.

Do I need a Will?

Yes. A will is the cornerstone of a successful estate plan. It is the only way to control the flow of assets from your estate after death.

Without a will, a parent's assests will pass along according to what is called intestate succession. Here is an illustration of that: suppose there is one remaining parent who dies leaving two sons. One son is a well-to-do physician who has no interest in the family. The other is a mentally handicapped man who lives in a state institution and has a lifelong need for care and supervision. The parent has an estate of $100,000 and when the parent dies, under intestate succession, each son will receive $50,000.

The planning, if there has been any at all, has left the disabled son inadequately provided for. Moreover, the $50,000 inheritance causes him to be no longer eligible for SSI and Medicaid. And if Medicaid had been funding his placement in an intermediate care facility, even that placement could be in jeopardy. He might, for example, be transferred to another res-

idential unit where less treatment and activities are available. His personal needs allowance under SSI would cease.

Most probably, the state would start billing him for the cost of institutional care, now about $20,000 a year. The $50,000 legacy, under those circumstances, would last less than three years and, once again indigent, he would be eligible to return to an ICF facility should a vacancy exist.

The result is the complete exhaustion of assets that took a lifetime to accumulate, without the disabled son having received any meaningful benefits from them. In fact, he suffers as a result of receiving them.

It could be done differently.

Let us suppose the father secured the appointment of his nephew as guardian and trustee for the retarded son, and then left the nephew $2,000 for any expenses he might incur. Through the will, the father leaves $98,000 in trust for the handicapped son to cover those needs which are not met under any governmental or charitable programs.

The guardian and trustee is bound by law to use the money in accordance with the terms of the trust. The money, therefore, could be available for additional clothing, recreation, programming and even vacations for the handicapped son. Prudently invested and managed, the trust could last a lifetime.

Should wills and other estate plans be reviewed regularly?

Certainly. Needs and circumstances change. For example, a young parent with two minor children, one of them severely handicapped, would want to protect them equally for a while. As the non-handicapped child matures, the need for protection lessens, while that of the disabled child could very well increase. An estate plan that remains unchanged would not address new conditions and circumstances.

Also, an ideal candidate to succeed parents as guardians can become a bad choice as time passes: people age or move away; relationships sour; accidents occur. Periodic review is strongly recommended.

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